Immunotherapy

A Booklet for Patients and Caregivers

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER
GILDA'S CLUB

Immunotherapy (IO) is a way to treat many kinds of cancer. It works by using your body's own defenses to identify and attack cancer cells. Your immune system works in many ways to identify unhealthy cells and attack them.

There are different kinds of immunotherapy. Some immunotherapies can boost your overall immune response. Others can help your immune system recognize cancer cells more clearly so it can fight them.

This resource includes:

- What immunotherapy is and how it works
- Who can get immunotherapy
- Types of immunotherapy
- What to expect when receiving immunotherapy
- Supportive resources

To learn more about immunotherapy, visit **www.CancerSupportCommunity.org/Immunotherapy-Cancer-It-Right-You**

WHAT IS IMMUNOTHERAPY?

Immunotherapy is a type of cancer treatment that uses the body's natural defenses (immune system) to identify, attack, and kill cancer cells. Normally, your immune system can recognize and destroy abnormal cells, but cancer cells learn tricks to hide or shut down immune responses. Immunotherapy helps "wake up" the immune system so it can do its job.

There are different kinds of immunotherapy treatments. They help fight cancer by:

- **Boosting the immune system.** A "revved up" immune system can be better at fighting cancer.
- **"Marking" cancer cells** so that your immune system can see them better to find and destroy them. This keeps cancer from being able to hide from the immune system.
- **Blocking the "brakes"** cancer cells put on the immune system, allowing immune cells to attack the cancer cells again.

The drugs used in immunotherapy may be made from natural substances produced by your own body — or from substances created in a lab.

IMMUNOTHERAPY TERMS

Immune system: A network of cells, tissues, and organs that work together to protect the body from bacteria, viruses, parasites, fungi, and abnormal cells like cancer cells.

T-cells: A type of white blood cell. T-cells are the immune system's "soldiers." They help protect the body from infection and can help fight cancer. They are also called T lymphocytes.

Antibody: A protein made by your body's immune cells to attach to a specific foreign invader, such as bacteria, viruses, and cancer cells.

Tumor antigen: A substance produced by a tumor cell that can cause the body to create a specific immune response.

Biomarker: A molecule in your body that your doctors can measure. Biomarkers give your doctor specific information about your cancer. Biomarkers can let doctors know if your tumor has a good chance of responding to a certain treatment.

WHO CAN GET IMMUNOTHERAPY?

While immunotherapy helps some patients live longer and better, it may not be an option for every patient or cancer type. You and your doctor might consider the following to help decide if you might benefit from certain immunotherapies:

- **Cancer type** – Immunotherapy is approved for many cancers, including bladder, breast (especially triple-negative), cervical, colorectal, esophageal, head and neck, kidney, liver, lung, lymphoma, prostate, and some skin cancers. Researchers are exploring ways to expand the use of immunotherapy in other types of cancer.
- **Biomarkers** – Immunotherapy works better when cancer has specific biomarkers (e.g., MSI-high, dMMR, PD-L1) or many genetic variations. Biomarker testing can help you find the treatment that is just right for you.
  - Learn more here: **www.CancerSupportCommunity.org/Biomarkers**
- **Your overall health** – To make sure immunotherapy is safe for you, you should not have an active autoimmune disease or be taking high-dose steroids. Some people with controlled HIV can still receive immunotherapy.
- **Stage of cancer and past treatments** – Your doctor will look at how advanced your cancer is and whether other treatments have worked.

Be sure to speak with your care team about the immunotherapy options for your specific cancer type. Although there are promising results, immunotherapy does not work for every patient who tries it.

TYPES OF IMMUNOTHERAPY

There are several types of immunotherapy for cancer. New treatments are being developed all the time, so this may not be a complete list. This list does not include clinical trials. For the latest information, go to **www.CancerSupportCommunity.org** and search for your tumor type to find out if new immunotherapy drugs have been approved.

Checkpoint Inhibitors

The immune system has safeguards in place to prevent it from attacking healthy cells. These safeguards are called checkpoints. They slow down or stop the immune system from attacking healthy tissue. Some cancers have learned how to activate these checkpoints to avoid being found and killed by the immune system. They trick the body into turning its own defenses off. Checkpoint inhibitors block these checkpoints, helping the body fight cancer.

Most patients who receive immunotherapy today are on a kind of checkpoint inhibitor: PD1, PDL-1, or CTLA-4 inhibitors. However, not all cancers can be treated with these drugs. These drugs may be given in combination with other treatments, such as chemotherapy or other immunotherapy drugs.

Bispecific Antibodies

Bispecific antibodies are lab-engineered proteins designed to bind to two different targets at the same time — one on a cancer cell and one on an immune cell. (The name reflects this: bi = two, specific = targets.) This makes them different from standard antibodies, which attach to only one target.

By latching onto both a cancer cell and a nearby immune cell at the same time, these drugs physically bridge the two together. This makes it easier for the immune system to recognize and attack the cancer. Some bispecific antibodies — often called T-cell engagers — work specifically by bringing T-cells to the cancer cell.

Other Monoclonal Antibodies

Checkpoint inhibitors are one type of monoclonal antibody (mAb). Other types of mAb let the immune system find and destroy cancer cells using targets that aren't checkpoints. Others take radiation or chemotherapy drugs directly to cancer cells. Each mAb is made to find and attach to a specific protein that occurs in cancer cells. Not all mAbs are immunotherapies; some are targeted therapies. Most mAb treatments that aren't checkpoint inhibitors are used in blood cancers.

Cell Therapy

In cell therapy, the body's own immune system cells (T-cells) are removed from a patient, taken to a lab, and modified. Once returned to the patient, these modified cells find and destroy cancer cells. The most common form of this treatment is CAR T-cell therapy.

For more information on CAR T-cell therapy, visit: **www.CancerSupportCommunity.org/CART**. Other cell therapies recently approved or being studied include TIL (tumor-infiltrating lymphocytes), TCR-T (engineered T-cell receptors), and CAR NK (engineered natural killer cells).

Treatment Vaccines

Treatment vaccines are designed to "teach" T-cells to find and attack cancer cells that have specific proteins. Treatment vaccines are made from the patient's own tumor cells, immune cells, or common antigens. These cells are sent to a lab where their ability to recognize and fight cancer cells is boosted. They are then re-infused into the patient.

Oncolytic Virus Therapy

Oncolytic means "something that destroys cancer cells." Oncolytic virus therapy uses viruses to fight cancer cells. Doctors inject a weakened or modified virus into your tumor. This virus infects and multiplies inside the cancer cells. The copies build up until the cancer cells burst and die. These bursting cancer cells signal the immune system to join the attack on cancer cells throughout the body.

Cytokines

Cytokines have been used for years. They do not target cancer cells like some newer treatment methods. Rather, they work by speeding up the growth of T-cells and activating other immune cells, boosting the immune system generally. Researchers are exploring the next generation of cytokine therapies.

WHAT ARE THE SIDE EFFECTS?

We tend to think of immunotherapy as "natural" — as our body's own defense system. However, immunotherapy can still have side effects. These effects are generally different from those caused by chemotherapy or radiation therapy. In many cases, they are not severe and may be short-lived or easy to manage. Less often, side effects can be very severe and even life-threatening.

Common Side Effects

- Flu-like symptoms (fever, chills, headache, nausea, cough, loss of appetite)
- Fatigue (some people get extreme fatigue)
- Rashes, redness, or itching
- Pain or soreness
- Muscle or joint pain
- Infections

Less Common Side Effects

- Colitis or other gastrointestinal problems (stomach pain, diarrhea, constipation)
- Problems with the thyroid, liver, kidneys, heart, or other glands or organs – Blood tests can identify issues within these organs.
- Lung problems (ongoing cough, shortness of breath) – A visit with a pulmonologist may help answer questions related to these issues.
- Other serious autoimmune conditions (such as pituitary disorders or diabetes)
- CRS (cytokine release syndrome), including fever, low blood pressure, or low oxygen
- ICANS (neurotoxicity), including confusion, word-finding trouble, or seizures

Sometimes the side effects do not occur right after treatment is given. They may show up several months later. Let your healthcare team know immediately if you notice any changes in side effects or symptoms. Most side effects can be managed if they are treated early.

HOW DOES IMMUNOTHERAPY COMPARE TO OTHER TREATMENTS?

You may be considering more than one treatment option for your cancer. The table below compares immunotherapy to other common cancer treatments. There are other treatment options that may be used to treat your cancer that aren't listed in this table. How often or how many sessions are needed for each treatment type may vary depending on your cancer type. Talk with your care team about what to expect with your treatment.

Treatment Type	How it Works	Where it is Given	Impact on Healthy Cells	How it is Administered	Common Side Effects
Immunotherapy	Boosts your body's immune system to attack cancer cells	Clinic or hospital	Limits harm to healthy cells	Infusion (IV) or injection	Fever, skin irritation, flu-like symptoms
Traditional Radiation (External Beam)	Radiation from outside the body	Clinic or hospital	May affect nearby healthy cells	Radiation machine/table	Skin irritation, fatigue, organ side effects
Chemotherapy	Drugs attack fast-dividing cells	Clinic, hospital, or home	Affects many healthy cells	Infusion (IV) or oral pills	Nausea, vomiting, hair loss, fatigue
Targeted Therapy	Targets specific genes or pathways that help cancer grow	Clinic or hospital	Can affect healthy cells with same targets	Oral pills or infusion (IV)	Fatigue, skin irritation, diarrhea, mouth sores, swelling

HOW IS IMMUNOTHERAPY GIVEN?

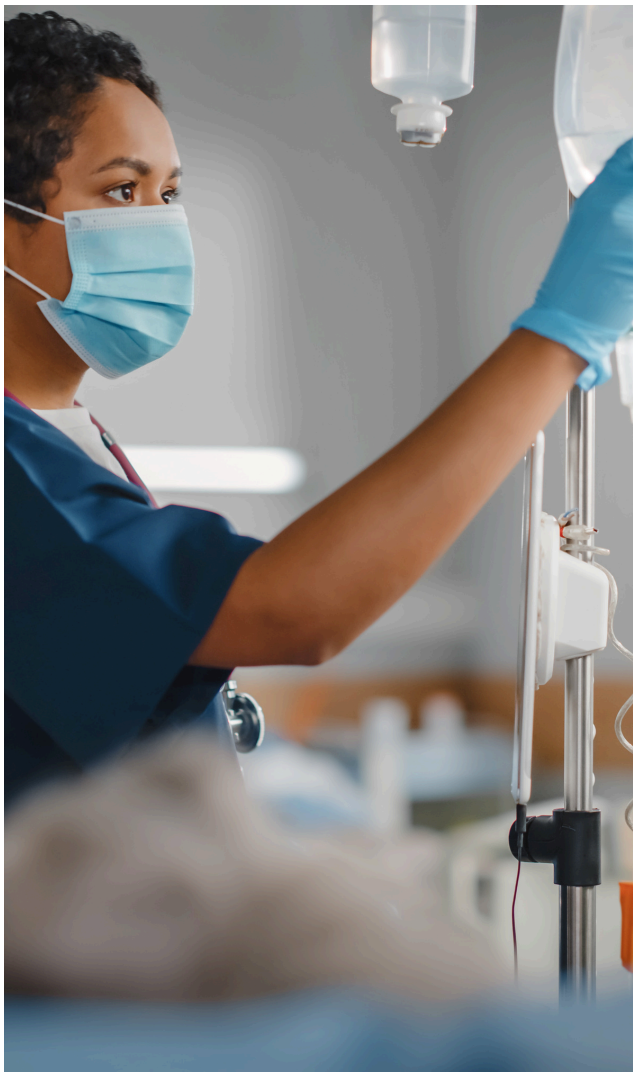
Most immunotherapy is given using an IV infusion (through a vein). You may also receive immunotherapy using a subcutaneous (under the skin) injection. You may receive immunotherapy in a doctor's office, in a clinic, or as a day patient in a hospital. Different immunotherapies are given on different schedules. Some may be given in combination with other treatments or with a different immunotherapy.

SUBCUTANEOUS (SC) IMMUNOTHERAPY

Subcutaneous means "under the skin." With SC immunotherapy, a cancer medicine is injected (like a shot) into the fatty layer beneath your skin. This is usually done in the stomach (abdomen) or thigh. This is different from IV immunotherapy, which is delivered directly into your vein during an infusion.

These injections typically take a few minutes, compared to IV infusions that may take 30 minutes to several hours. SC injections are given by a trained healthcare professional. You will not need to give yourself the injection.

Most SC immunotherapy drugs are the same medicines used for IV immunotherapy — only the delivery method is different. Several checkpoint inhibitors are now available in SC form. Researchers are continuing to develop new SC options, so more patients can benefit from this approach. SC options may help patients with less access to an infusion center. These options may also reduce clinic visit time and lessen the need for an IV access device (e.g., port, PICC line).



OTHER CONSIDERATIONS

Vaccines – Talk to your doctor about routine vaccines while on immunotherapy. Your doctor may recommend you still get your seasonal flu, COVID-19, RSV, and other vaccines, which are inactivated vaccines. Your care team may advise against live vaccines (e.g., MMR, chicken pox) while on immunotherapy.

Fertility, pregnancy, and breastfeeding – Checkpoint inhibitors can affect pregnancy and a newborn's immune system, if breastfeeding. Always discuss plans for pregnancy or breastfeeding with your care team before starting treatment.

WHAT DOES IT COST?

Many new treatments and treatment-related costs, including immunotherapy, can be very expensive. If you are being treated through a clinical trial, you may have those costs covered. Talk to your care team upfront about the financial issues involved in your treatment. Also, talk to your insurance company before beginning treatment to find out what the costs will be. Many treatment centers have resources to help patients obtain insurance coverage or will help you access grant programs designed to help cover costs of treatment.

If you or your loved one has questions about immunotherapy, including ways to cover the cost if it, call our Cancer Support Helpline at CSC-867-5309.

IS A CLINICAL TRIAL RIGHT FOR ME?

Be sure to ask your care team about any available clinical trials that you may be eligible for. Clinical trials are research studies that test new treatments or explore better ways to use existing treatments, including for different types of cancer. Ask about the potential benefits and risks.

Even if you can't get standard immunotherapy right now, joining a clinical trial might allow you to try new treatments that are being researched and developed, including different types of immunotherapy. Ask your doctor about all of your options, including whether a clinical trial may be right for you.

For more information on clinical trials and how to find them, refer to **www.CancerSupportCommunity.org/Clinical-Trials**.

QUESTIONS TO ASK YOUR CARE TEAM

Remember, YOU are your BEST advocate. Here are questions you can ask your care team:

Do you recommend immunotherapy for me? If so, what type?
Has my tumor been sent for biomarker testing? If so, what do the results mean for me?
Was my tumor tested for the PD-L1, MSI-H, or dMMR biomarkers? If so, does that give me more treatment options?
Are there any clinical trials for immunotherapy that would be right for me? How do I find out more about them?

For each treatment or clinical trial that is recommended:

Why do you recommend this type of therapy for me?
What is the goal of this treatment? What are the risks?
How will I receive this treatment? How often and how long will each session take?
Where will I go to receive treatment?
What side effects should I expect (short and long term)?
What can I do to prepare for immunotherapy treatment?
Will I need someone to drive me home after treatment?
Can/should I eat before or after treatment?
How long will I need to be on this treatment?
How will we know if this therapy is working?
How much will this therapy cost?
Will I need other cancer treatments at the same time?
How will this treatment impact my daily routine? Will I be able to do my usual daily activities?
Whom should I call if I have questions or problems during office hours? • Name: • Phone Number:
After hours and weekends? • Name: • Phone Number:

RESOURCES

IMMUNOTHERAPY RESOURCES

Cancer Support Community
CSC-867-5309 (or outside the U.S., toll-free 888-793-9355)
www.CancerSupportCommunity.org/Immunotherapy-Cancer-It-Right-You

American Cancer Society
800-227-2345
www.Cancer.org/Cancer/Managing-Cancer/Treatment-Types/Immunotherapy

National Cancer Institute (NCI)
800-422-6237
www.Cancer.gov/About-Cancer/Treatment/Types/Immunotherapy

NCI Clinical Trial Information
800-422-6237 | www.Cancer.gov/ClinicalTrials

Patient Advocate Foundation
800-532-5274 | www.PatientAdvocate.org

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline (CSC-876-5309 or outside of the U.S., toll-free 888-793-9355), available in 200 languages.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling CSC-867-5309 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more **www.CancerSupportCommunity.org/FindLocation**.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Immunotherapy-Cancer-It-Right-You**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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LUNGEVITY Transforming Lung Cancer
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This publication was made possible through generous support from:

Bristol Myers Squibb®

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